



PHASE TWO
REGIONAL REPORT RELATING TO
CARE IN YOUR OWN HOME
OCTOBER 2015



Foreword

I am pleased to present the regional report on the findings from the second phase of the '10,000 Voices' Initiative. This Initiative has been commissioned and funded by the Health and Social Care Board (HSCB) and the Public Health Agency (PHA) to introduce a more patient focused approach to shaping the way services are delivered and commissioned. It is important for us to 'see and hear' through the eyes and ears of the patient and remember that that each experience is unique for every patient/client. 10,000 Voices provides a mechanism for patients and clients not only to share their experience of the health services, both positive and negative, but also to affect and inform change.

Patient and client experience is a key indicator of quality and is central to many of the strategic drivers for health and social care improvement and innovation. For instance 'Patient and Client Focus' is one of three key elements outlined in the Quality 2020 Strategy (DHSSPS 2012) and highlights that all patient and clients are entitled to be treated with dignity and respect and should be fully involved in decisions effecting their treatment and support. In addition, Transforming Your Care" (DHSSPS 2011) focuses on reforming and modernising services, so that they are centred on people rather than institutions, therefore placing patient and client experience at the heart of health and social care reform.

Transforming Your Care aims to make home or the community the hub of care and to prevent, where possible hospital admission. It is therefore very timely that through the 10,000 Voices Initiative we extended the second phase to hear about the experiences of those who receive care in their own home. To date (30 September 2015) we have received a total of 1399 stories from patients, carers and families who receive care in their own home.

I am delighted that so many people have taken the time to share their experiences of Health and Social Care through the 10,000 Voices Initiative and wish to thank all those who participated; their contribution has been invaluable and will undoubtedly influence the delivery and commissioning of services.

Mary Hinds

Executive Summary

This report presents the analysis of the information which has been received during Phase 2 of 10,000 Voices (February 2014 –September 2015) from patients/clients/carers and family members who receive care in their own homes.

Engagement to collect stories from clients and their families who receive care at home took place across a broad range of areas and settings. A total of 1399 stories have been received to date and the facility for collecting stories remains live. Sixty percent of the stories were submitted by the person who received the care, with the remaining being completed on behalf of the person receiving the care, by carers or by a family member. The majority of respondents were older people with 72% over 70 years of age and the largest age group of clients receiving care at home was the over 80 age group. (Page 11)

Most of the care was delivered by domiciliary care workers, including home helps, home care staff and health care assistants, however there was also a range of other professional groups and staff involved in care delivery. (Page 13)

A high proportion of clients and their families who care for them report that their overall feelings about receiving care in their own home are positive or strongly positive. These people have told us that they are very appreciative of the care they/their family members receive, they want to remain as independent as possible and they want to remain at home for as long as possible. Many consider their carers to be professional, caring and helpful, however some of these clients and their carers also report that their care needs are not always met in the allocated time. For people who have been receiving care in their home over a prolonged period of time, many consider their carers to be like their friends and family, however both clients and their family members have some anxiety if they do not have the same carers providing their care.

The remaining clients and their family members who report their overall feelings to be less positive have told us that they feel the carers who visit their homes are very rushed and do not always have enough time to deliver their care and that they also feel that they don't have enough input into decisions about their care. Meeting care needs in the allocated time varies across the professional groups and support

services who provide the care (Page 15-18). A small proportion of clients find that on occasions staff can be abrupt and do not always behave in a respectful way towards them.

Many of the stories highlight the isolation and loneliness that people who live alone experience and how they are very grateful for the company and security that staff provide when they are delivering care. For residents who live in sheltered accommodation or supported living and receive care in this setting, many describe the positive aspects of living in this type of accommodation as well as a high level of satisfaction with their care.

Most clients have told us that they want to remain in their own home for as long as possible with the adequate level of care delivered in a timely and responsive manner. In addition many of those who participated and identified themselves as carers stated that they could not cope with their caring responsibilities without the support they receive from the staff who deliver care in the home of the person they are caring for.

It is clear that there are lot of positive messages in the information which has been obtained from clients who receive care in their own home. It is important that these positive messages are shared with the relevant staff, with members of the public as well as with those who commission services. Areas for action to improve the experience of people who receive care in their own homes have been identified through the local Trust findings and are being progressed.

There are a number of emerging issues which will require a regional approach in progressing actions to improve their experience of people who receive care in their own homes. These are:

1. Isolation and loneliness: Many stories describe the isolation and loneliness experienced by people who live alone and who depend on carers coming into their homes; these stories indicate that these clients are very appreciative of the service which is provided to them. For many of these people their carers are the only people they see on a day to day basis. People who attend day centres appreciate and enjoy

the company that they receive and for those who live in sheltered accommodation they enjoy the comfort and security that this type of housing offers.

Action: As it is recognised that social isolation extends to broader areas than health and social care, one of the best mechanisms to address this will be by working collaboratively with individuals, communities and partner organisations through the implementation of Making Life Better (DHSSPS 2013- 2023). The first steps to progress this action will include a workshop with key stakeholders.

2. Timing of calls and time allocation: In the analysis of the stories it is clear that people feel staff are rushing to get everything done in the time allocated, and that although the carers do the best they can, needs are often not met and clients frequently have to rely on family and friends to provide further assistance. The timing of calls is not always suitable to client's lifestyle, for example many clients and their family members feel that they return to bed too early in the evening, also timings can be inconsistent at times.

Action: The findings from this phase of 10,000 Voices have been recognised in the review of domiciliary care in Northern Ireland and will be addressed through this review.

3. Care of clients with dementia: Some stories indicate that those providing care do not always have adequate knowledge and skills to care for clients with dementia.

Action: The findings in relation to the knowledge and skills of staff will be addressed through the NI Dementia Learning and Development Framework, which is currently being developed by HSCB and PHA.

4. Communication: Some stories highlight that there can be inconsistency in who delivers the care and this often leads to mixed messages in communication with the client not always knowing who is caring for them. It is therefore vital that all staff introduce themselves and wear name badges. It is also important to clients that their carers know *what matters* to them before leaving their house, for example– drinks, phones at reach, pull back curtains.

Some respondents indicate that they are not always sure what happens to their personal information (11%), with stories highlighting a lack of privacy within their own home.

Actions: The actions in relation to communication, including informing clients what happens to their personal information, will continue to be addressed by Trusts. For those who receive care at home on a long term basis wherever possible the care should be provided by a consistent team of carers who have established a relationship with the client. Extending the ***Hello my name is*** campaign to community settings has been included as a Patient Client Experience priority regional for 2015/2016.

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1.0 Introduction and background

The PHA / HSCB commissioned the 10,000 voices Initiative to enable engagement with patients/clients to focus on **what matters** to them as well as **what is the matter** with them when using health and social care services.

The 10,000 Voices Initiative asks patients to share their experience of health and social care services by “telling their story”. This is important because national and international evidence has shown us that ‘patient stories’ provide an insight into the services provided and therefore make them an appropriate method to improve the quality of care.

This approach is in keeping with the PHA/HSCBs commitment to involve patients, carers and families in how services are shaped and delivered in Northern Ireland (NI) and all HSC Trusts are involved with this Initiative. The 10,000 Voices Initiative will focus on a range of areas across health and social care to the gain patient and client experience.

In response to the increasing ageing population and the numbers of people living with long term conditions, more people are being facilitated to live at home or closer to home with the appropriate care. Currently over 24,000 people in Northern Ireland receive domiciliary care in their own home (DHSSPS 2015). Phase two of the 10,000 Voices Initiative has provided an opportunity for people to tell us about their experience of receiving care in their own home.

2.0 The Survey

The survey, which uses Sensemaker® methodology, was designed with public engagement through a series of workshops across NI at which patients, families, carers, and HSC staff participated.

Those filling in the survey are asked to tell us about their experience of receiving care in their own home, to help others to understand what it is like from a patient perspective. They can choose to share all or part of their experience. The survey can be completed by the patient themselves, their carers, family or others. They are asked to respond to a series of questions, which are formatted in the shape of a triangle. In each of these questions the respondent reviews 3 statements and places

a “dot” nearest to the statement that reflects their experience. They complete the survey by answering a few multiple choice questions.

2.1 Accessibility

The survey has been promoted through a variety of ways. Trust Facilitators have engaged with patients, carers and families in a range of areas, including community groups, shopping centres, schools/colleges and factories, residential facilities, sheltered housing associations as well as within hospital settings. The survey can be completed using a paper copy, online or through a Digital App. It has been translated into 6 languages (Chinese simple, Chinese complex, Latvian, Slovak, Lithuanian and Polish) and can also be completed using a voice recording facility on the App.

2.2 Completing the survey

Patients, clients, carers and family members are asked not to give their name or the name of any staff that provided care and are advised not to worry about spelling or grammar. They are asked to give their story a title and to select key words which describe their experience, the titles and key words are often indicative of the nature of the experience the person has had. Some of the titles which have been provided by people who receive care in their own home are shown below:



It is clear that people appreciate the opportunity to provide feedback on their experience as shown in the comments below:

I value all service received, particularly value obvious ongoing evaluation of service provision, of which this survey is an example and feel privileged to be a part of the 10,000 Voices submitting opinions with a view to continuously improve standards of care.

Thank you for taking the time to talk to me

3.0 The Results

Phase two of the 10,000 Voices Initiative commenced in February 2014 and the patient stories received until 30 September 2015 have been included in this review.

The table below shows the number of stories received in each Trust area:

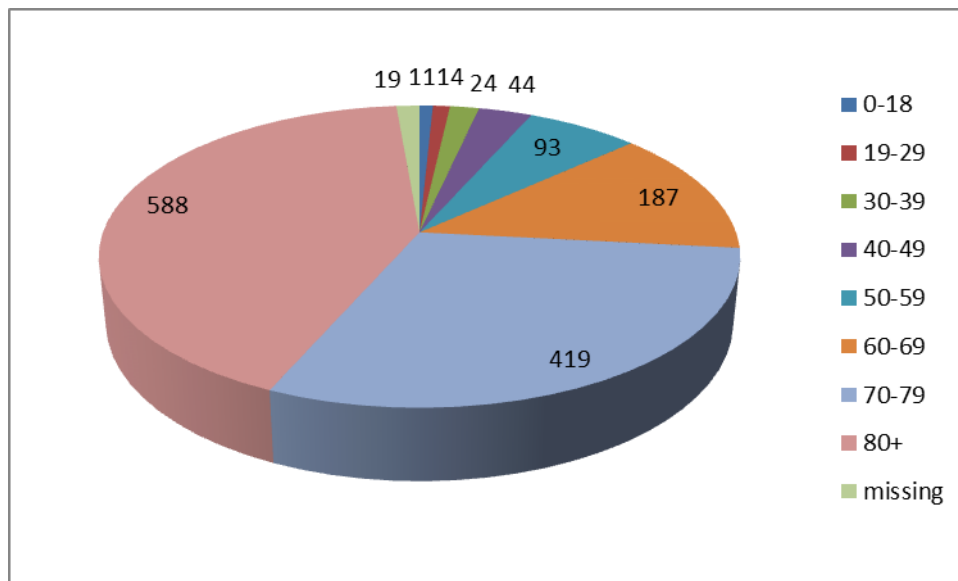
Area	Number of stories received
Belfast Health and Social Care Trust	285
Northern Health and Social Care Trust	152
Southern Health and Social Care Trust	187
South Eastern Health and Social Care Trust	394
Western Health and Social Care Trust	381
Total	1399

Who completed the survey?

- ❖ 60% completed by person receiving care
- ❖ 23% completed on behalf of person receiving care
- ❖ 10% completed by carer
- ❖ 7% completed by other person (family member)
- ❖ 66% stories relate to care provided by Trust staff
- ❖ 62% female, 37% male, 1% missing data

Age group of respondents

The majority of participants were older people, with 42% over 80 years of age, representing a client group who are increasingly dependent on others to have their care needs met and who are often frail and vulnerable individuals, many of whom have ongoing, long term complex needs. The chart below shows the number of responses per age group.



Stories were collected from a range of settings, for example:

- Domiciliary care in clients own homes
- Supported living facilities
- Rehab and re-enablement
- Community Nursing Rapid Response Service
- District Nursing
- Hospital diversion teams
- Floating support workers (Rathlin Island)
- Occupational therapists/ Physiotherapists
- Community Children's Nursing Service

Who provides the care?

Participants are asked to identify who provides their care, as can be seen in the table below the majority of stories included in this review were from clients whose care is provided by Trust staff: For clients who indicated *other* their care was often provided by a combination of Trust staff and independent providers and family members

	Regional total	BHSCT	NHSCT	SEHSCT	SHSCT	WHSCT
Trust staff	928 (66%)	183 (64%)	99 (65%)	246(62%)	128 (68%)	272 (71%)
Independent provider	204 (15%)	54 (19%)	20(13%)	80 (20%)	20 (11%)	30 (8%)
Not sure	134 (10%)	25 (9%)	12 (9%)	34 (9%)	29 (16%)	34 (9%)
Other	133 (9%)	23 (8%)	21 (14%)	34 (9%)	10 (5%)	45 (12%)
Total	1399	285	152	394	187	381

Who delivers the care?

Care delivery to clients who live at home is often provided by several health care professionals and support services who are involved in both the assessment and review of care needs and the actual delivery of care. Participants are asked to identify which health care professionals/ support services are involved in their care, in many cases they identify more than one service. Therefore the numbers are not reflective of the total number of patients but rather the number of patients who have can identify with a particular service.

Ninety per cent of respondents identified domiciliary care staff, home helps and health care assistants as the providers of their care. However 36% identified AHPs, 29% social workers /assessors and 13% nursing, reflecting the range of professions involved in providing care at home.

Table 3 below presents the breakdown of staff and services identified:

Table 3: Breakdown of staff involved in providing care						
Services Provided	BHSCT	NHSCT	SEHSCT	SHSCT	WHSCT	Total Numbers
Domiciliary Care / Home Help / Home Care Staff / Health Care Assistants	265	114	423	156	301	1259
Social worker/assessor	66	36	97	64	143	407
Rapid Response / CNRRS / Hospital Diversion Teams	2	11	51	0	11	74
District nursing / Specialist Nursing	12	21	10	11	58	112
AHP including Physiotherapist / OT / Podiatry / Speech and Language Therapist	54	56	189	73	135	507
Sheltered Housing / support housing Services	24	0	36	7	0	67
Rehab/Re-ablement Services	0	0	6	5	2	15
Mental Health Services	1	0	2	5	7	15

Overall satisfaction with care provided at home

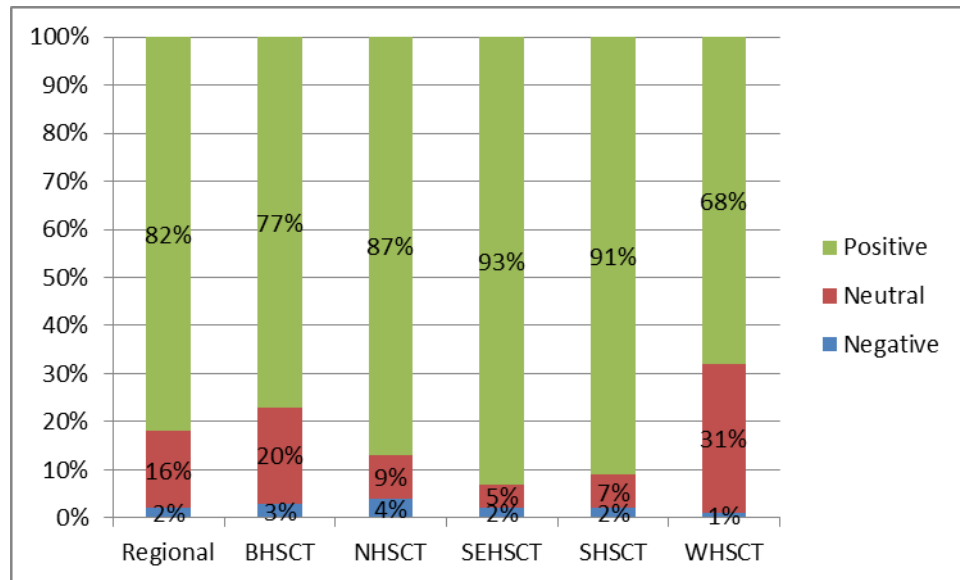
When asked about their overall feelings about their experience of receiving their care at home, a high percentage (79%) of clients rated their experience as strongly positive or positive. The key messages in stories which highlight positive aspects of patient experience are appreciation of being able to remain at home and remaining as independent as possible. Many clients report that they find that their carers are kind, helpful, understanding, caring and compassionate and providing outstanding care, however they also recognise that frequently the carers are rushed and do not always have enough time to deliver their care in the allocated time or at a time suitable to them.

Impact of receiving care at home

Whilst 79% of clients stated their overall feelings about receiving their care at home was positive or strongly positive, 82% also state that the impact of receiving their care at home has been strongly positive or positive, with 3% negative or strongly

negative and 15% not sure or neutral. Maintaining Independence was reported as one of the most positive aspects of receiving care at home.

There are some variations noted in the responses from the individual Trusts as shown below in relation to the impact of receiving care at home.



The number of stories which are rated to neutral/not sure is highest in BHSCT and WHSCT, key messages in these stories are as follows:

- Inconsistency in the carers who provide the care
- Getting the care package established
- Needing additional help
- Timing and time allocation of calls
- Feeling safe in place of care

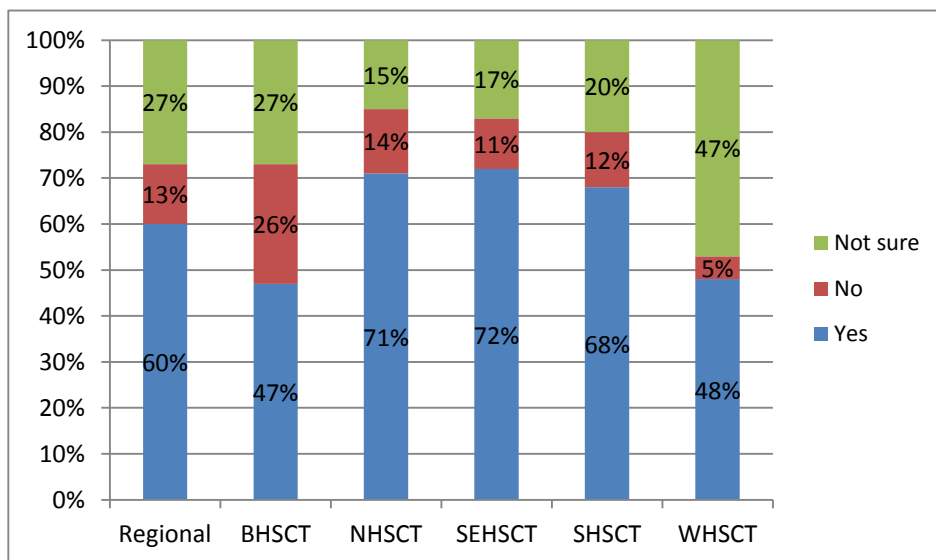
Experience of care was obtained from 3 Trusts (BHSCT, SEHSCT and SHSCT) from clients who live in sheltered accommodation/supported living. The individual stories reflect very positive experiences with this type of accommodation and the associated care and overall the vast majority of these clients report that the impact of receiving their care in this setting was strongly positive/ positive.

Meeting care needs in the allocated time:

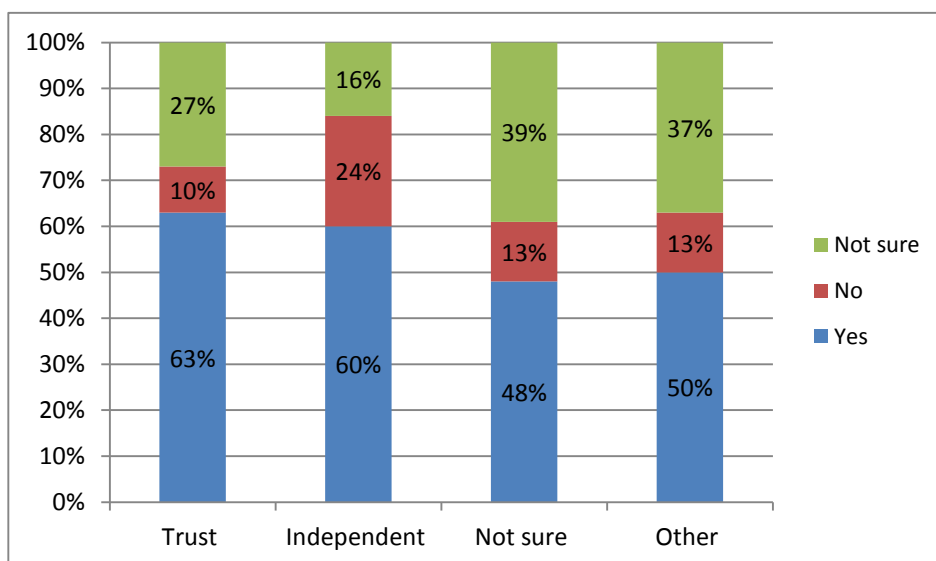
Almost two thirds reported that they are aware of the time allocated for delivery of care in their own home, 28% were not sure what time is allocated and 11% do not know what time is allocated for their care. Many of the stories reflect that clients feel

their needs are not met in the allocated time as illustrated in the response to the question: ***Do you feel your care needs are met in the allocated time?*** There is some variation between the Trusts in the overall responses to this question as shown below:

Overall responses to: ***Do you feel your care needs are met in the allocated time?***



Responses in relation to care being met in allocated time by who provides the care are shown below:

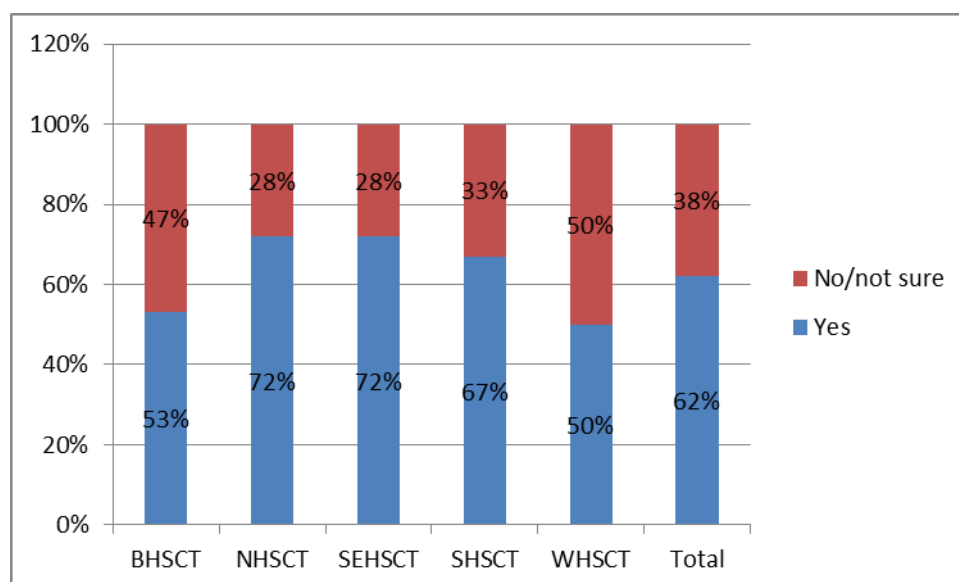


Commentary

This is analysed further, as illustrated below for patients who identified domiciliary care, home help, home care and health care assistants as being involved in delivering their care. Almost three quarters of clients in NHSCT and SEHSCT felt that their care needs were met in the allocated time, with 67% of clients in SHSCT. It is noted that there is a higher percentage of patients who state that their care needs are not met or are not sure if they are met in the allocated time in BHSCT and WHSCT (47% and 50%) for this group of clients.

Domiciliary Care / Home Help / Home Care Staff / Health Care Assistants:

Are your care needs met in the allocated time?

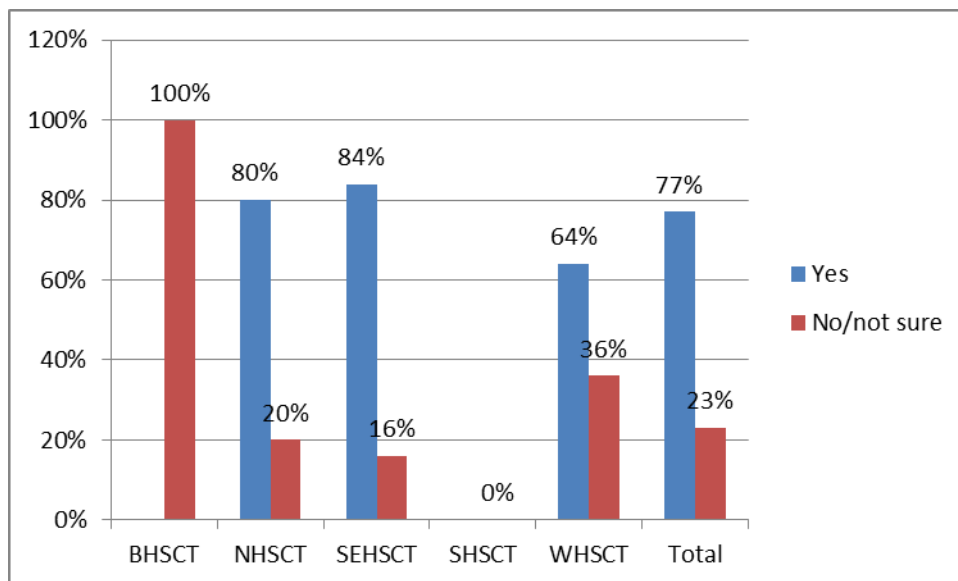


Are your care needs met in the allocated time?						
	BHSCT	NHSCT	SEHSCT	SHSCT	WHSCT	Total
Total	265	114	423	156	301	1259
Yes	53%	72%	72%	67%	50%	62%
No/not sure	47%	28%	28%	33%	50%	38%

For clients who receive input from nursing services, a higher percentage of people feel their care needs are met in the allocated time when this is provided on a short term focused period, for example administration of blood or intravenous antibiotics by a rapid response team/hospital diversion team. These people are very grateful that they can receive this high level of care in their own home, thus avoiding hospital admission.

Rapid Response / CNRRS / Hospital Diversion Teams:

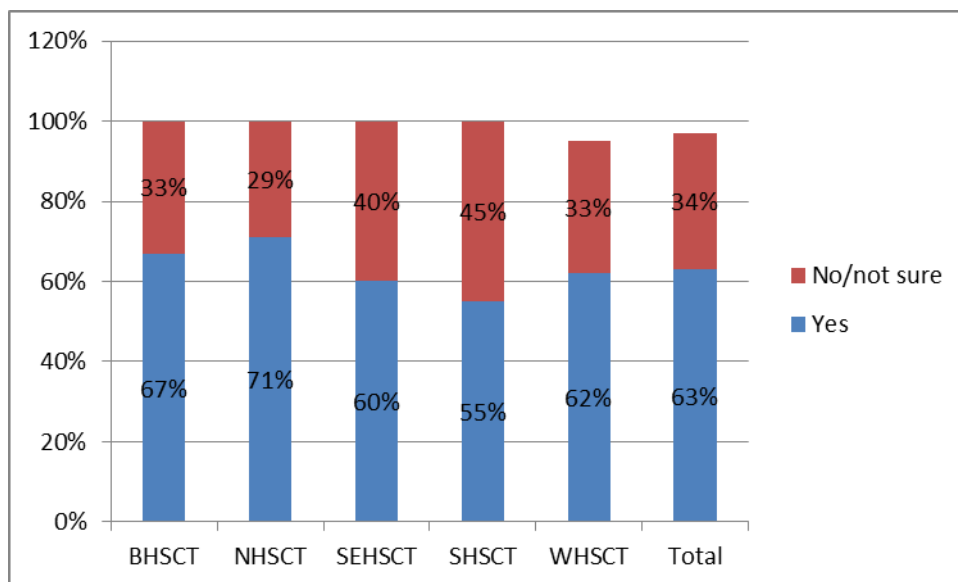
Are your care needs met in the allocated time?



Are your care needs met in the allocated time?						
	BHSCT	NHSCT	SEHSCT	SHSCT	WHSCT	Total
Total	2	11	51	0	11	74
Yes	0%	80%	84%	0%	64%	77%
No/not sure	100%	20%	16%	0%	36%	23%

Stories from clients who had care provided by district nurses and specialist nurses were included in this review . The numbers are much lower than other professional groups, therefore the ability to make comparisons is somewhat limited. Information in the patient stories indicate that the clients who have identified district or specialist nursing as being involved in delivering their care, have on going, long term and often complex needs with many reporting that their care needs are not met in the allocated time. However as the majority of these people also receive care from a range of other professionals and support services, when examining the responses in relation to time allocation, this needs to be considered across the range of services and not attributed solely to district nursing.

District nursing / Specialist Nursing



Are your care needs met in the allocated time?						
	BHSCT	NHSCT	SEHSCT	SHSCT	WHSCT	Total
Total	12	21	10	11	55	109
Yes	67%	71%	60%	55%	62%	63%
No/not sure	33%	29%	40%	45%	33%	34%

4.0 Responses to signifiers

This section provides the responses to the survey questions with relevant extracts from the patient stories. It should be noted that the percentage ratings are approximate and represent the cluster responses at each of the corners of the triangle only and do not account for the response which are outside these areas. The responses to the questions have been colour coded to represent the Trusts as follows:

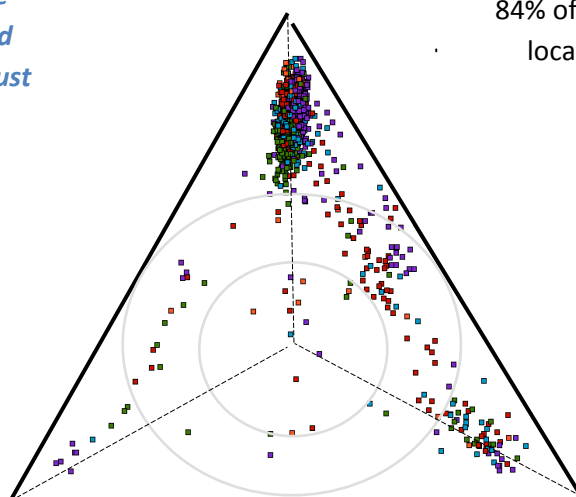
Belfast Health and Social Care Trust	
Southern Health and Social Care Trust	Northern Health and Social Care Trust
Western Health and Social Care Trust	South Eastern Health and Social Care Trust

Q1: Where would you choose to have your care?

I am delighted that I can be cared for at home

I live on my own and have carers come in the am and evening, they have only just started and have made a huge difference

We both want to be together at home but I think this is going to be impossible as I will not be able to get more hours of help



84% of stories are located here

I am very grateful for the care package I receive and my carer goes above and beyond for me. I am given care at home and getting the right treatment.

I think it would be more appropriate to go to hospital/other care environment

I like being at home but am not sure that I receive everything I need

Distribution of % responses across Trusts:

Response	BHSCT	NHSCT	SEHSCT	SHSCT	WHSCT	Overall
I am delighted that I can be cared for at home	73%	84%	81%	85%	89%	84%
I think it would be more appropriate to go to hospital/other care environment	0%	0%	2%	0.5%	1%	1%
I like being at home but am not sure that I receive everything I need	8%	2%	4%	9%	4%	6%

Discussion:

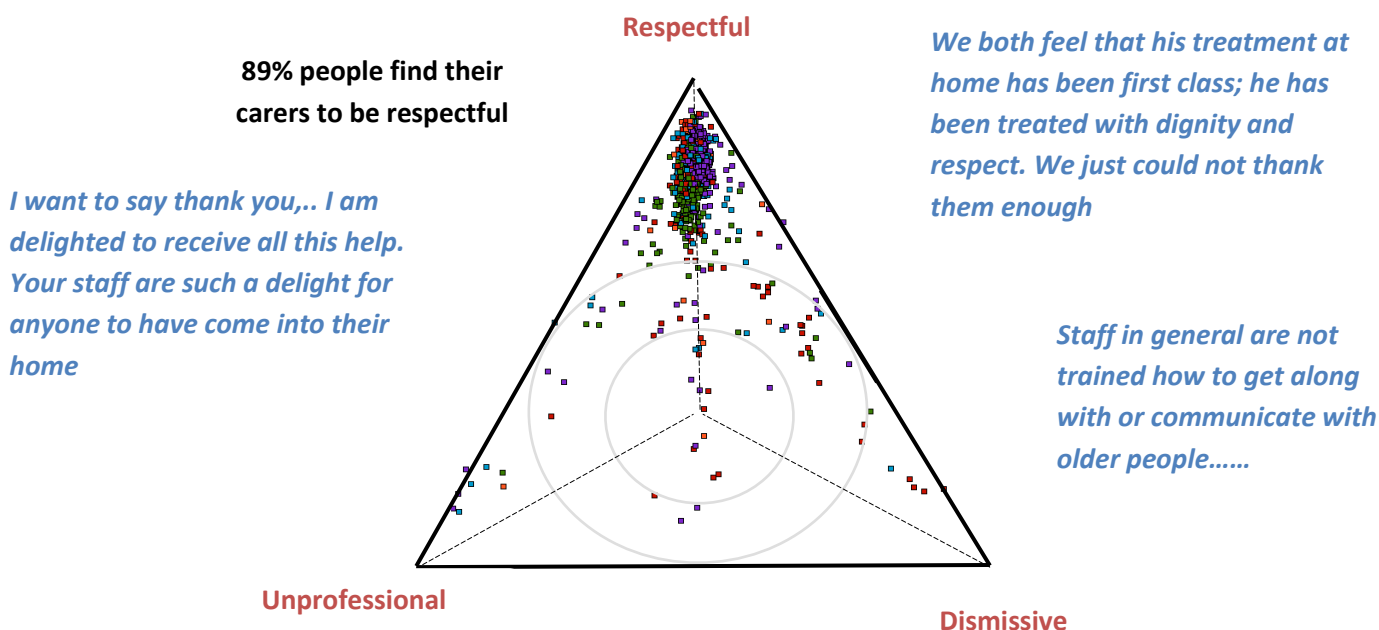
The majority of people (84%) are delighted that they can be cared for at home, with many stories describing the respect and compassion shown by a range of staff, who assess, plan, deliver and review their care. These stories also indicate the appreciation of people who can receive care which enables them to continue to live

in their own home. To most clients being cared for at home appears to have a positive impact on their independence and how they feel.

Around 6% like being at home but are not sure that they receive everything they need and many report that they feel lonely and isolated. These stories have the following key messages: Staff do not always have the adequate skills and knowledge to care for patients with dementia, the issue of the time allocation for delivery of care is further noted and clients sometimes find that the carers are abrupt in their attitude.

A small minority of people think it would be more appropriate to go to another care environment, which includes remaining in hospital or going to a fold.

Question 2: Overall do you feel that the carers are?



Distribution of % responses across Trusts:

Response	BHSCT	NHSCT	SEHSCT	SHSCT	WHSCT	Overall
Respectful	85%	89%	89%	92%	93%	89%
Unprofessional	0%	1%	0.5%	1%	0.5%	0.5%
Dismissive	0.5%	0%	0.5%	0.5%	0%	1%

Discussion:

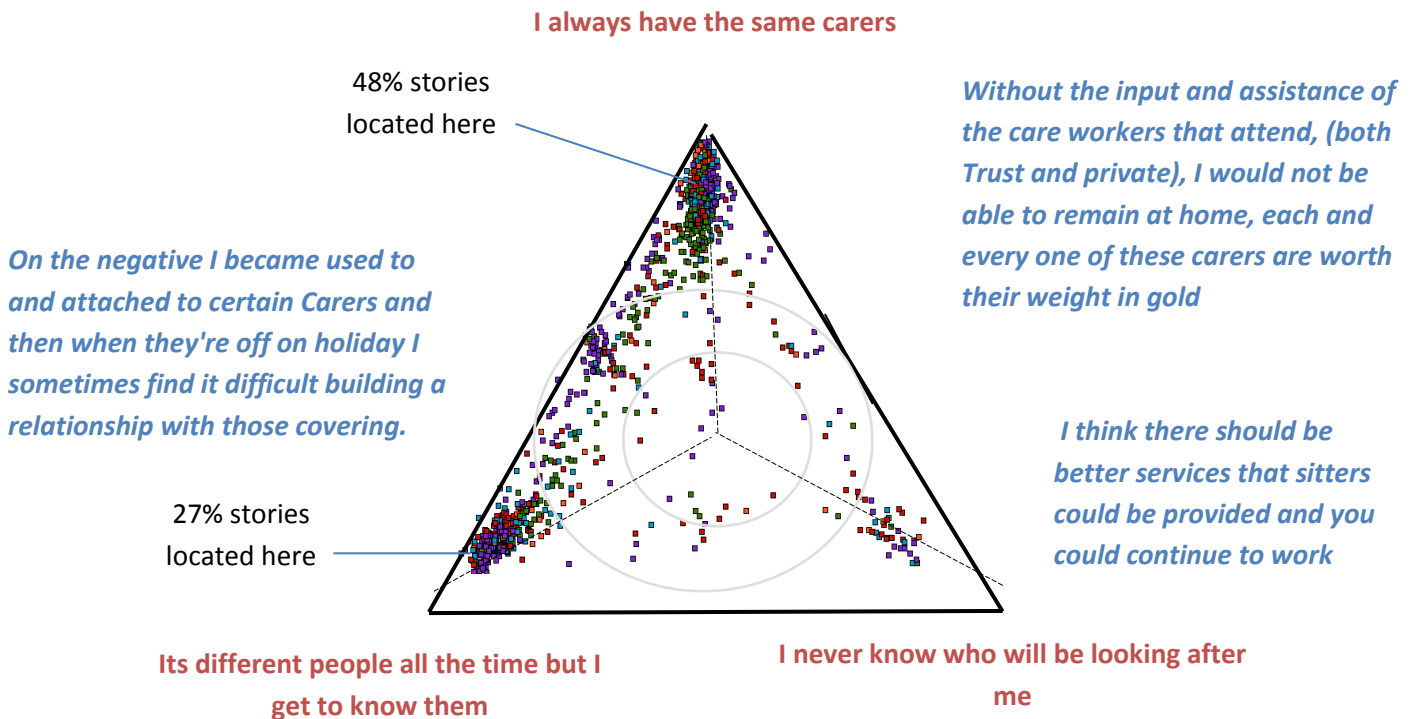
It is very encouraging to note that overall 89% of clients find their carers to be respectful, an example of one of the stories, encompassing members of the multi-disciplinary team is shown below:

.....was on many pills and still am. I couldn't stand alone.I can now walk with a rolator and stand independently for 4 minutes. I have climbed my 12 stairs with help behind me. Every day I have Carers to get me out of bed and washed, breakfasted and comfortable and I am progressing each day. Carers also make my lunch. My family look after my care after lunch time. I feel so delighted to be on my feet again. The encouragement from Physiotherapists has been marvellous.The carers and healthcare assistants are pleasant and considerate; they are cheerful

workers and are always willing to help. The Social Worker is considerate of my needs. The physiotherapist is always helpful and the OT is a great help and the advice of both means I make new advances with each visit.

For the small minority of clients who feel that staff are unprofessional or dismissive, the main areas of concern are lack of privacy, not having time for the individual as a person, care of patients with dementia and staff not attending satisfactorily to personal care needs.

Question 3: Do you always know will be providing your care?



Distribution of % responses across Trusts:

Response	BHSCT	NHSCT	SEHSCT	SHSCT	WHSCT	Overall
I always have the same carers	41%	45%	40%	52%	66%	48%
Its different people but I get to know them	32%	32%	27%	34%	16%	29%
I never know who will be looking after me	6%	6%	3%	4%	2%	4%

Discussion

Almost half of the participants overall report that they have the same carers all the time and they feel very comfortable with these carers coming into their home on a regular and ongoing basis. The percentage of clients who always have the same carers is highest in the WHSCT and lowest in SEHSCT.

In some cases this care package has been in place for a number of years with one client saying he has had the same carer for 15 years. Some stories consider the carers to part of the family, with statements like “she is like a daughter to me”.

Over a quarter of responses, with some variation cross the Trusts and groups of staff, indicate that although clients have different people looking after them they do get to know them and a small number (4%) never know who will be looking after them. It is also vital that when clients meet carers for the first time that they introduce themselves, not only to initiate a therapeutic relationship but also to instil a sense of safety and security for the client.

It is noted that in this triad there are also a substantial number of responses at the left side in between the two responses. These stories indicate that clients sometimes find it difficult to get to know their carers. While it is recognised that there will be circumstances when it is not always be possible for the same carers to be present, there is a need to ensure that a consistent and individual approach to care is co-ordinated.

Question 4: Do you feel your needs are always met by the care you receive?



Distribution of % responses across Trusts:

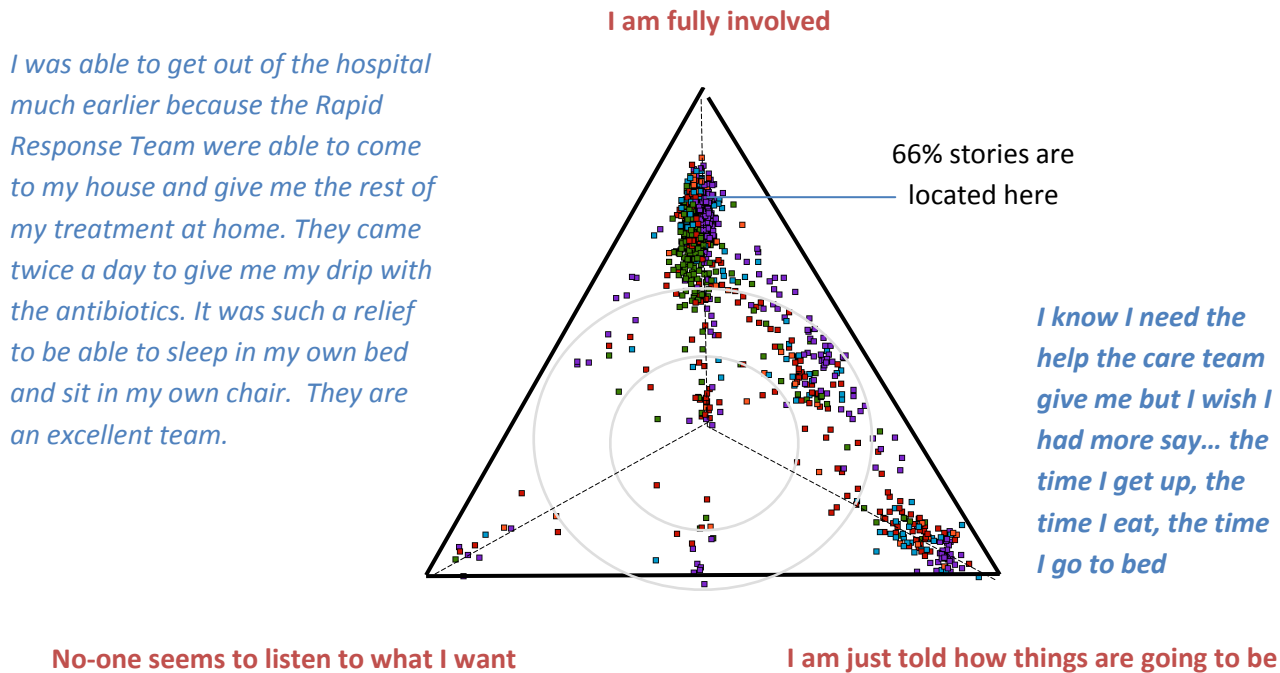
Response	BHSCT	NHSCT	SEHSCT	SHSCT	WHSCT	Overall
I frequently have to ask for further help for my needs	10%	13%	9%	6%	4%	8%
The carers always do their best to make sure my needs are met	46%	59%	55%	55%	65%	58%
I rely on family or friends to meet my needs	5%	3%	2%	8%	5%	4%

Discussion

The time allocation to deliver care is a consistent theme throughout the responses to this question in all Trusts and clearly impacts on the areas of satisfaction with care. It is interesting to note that in the response to the question: **Do you feel your care needs are met in the allocated time** the highest percentage of no/not sure response were attributed to the WHSCT, whilst in the responses to this signifier in the WHSCT 65% of clients feel that the carers do their best to make sure their needs are met

Overall, 58% feel the carers do their best to make sure care needs are met, however there is also a cluster of responses in between the two statements: ***The carers always do their best to make sure my needs are met*** and ***I rely on family or friends to meet my needs***, which when added to the remaining responses equates to almost a quarter having to ask for further help or rely on family and friends to provide additional support. Some of these stories have been written by carers who feel that the level of care is inadequate as highlighted in the story above.

Question 5: How involved are you in planning your treatment?



Distribution of % responses across Trusts:

Response	BHSCT	NHSCT	SEHSCT	SHSCT	WHSCT	Overall
I am fully involved	52%	75%	61%	67%	85%	66%
No-one seems to listen to what I want	1%	2%	2%	0.5%	0.5%	1%
I am just told how things are going to be	15%	9%	9%	19%	3%	10%

Discussion

Overall, two thirds of clients feel that they are fully involved in planning in their treatment, which is vital in promoting a person centred approach to care and treating the person as an individual. There is some variation in the responses across the Trusts with a higher proportion of clients in WHSCT and NHSCT indicating that they feel fully involved in planning their treatment. Many of these people who receive care at home have ongoing and complex needs and have input from a number of professionals and support services over a prolonged period of time.

The remaining responses distributed throughout this triad indicate that people feel partially involved in planning their treatment, with 10% reporting that they are just told how things are going to be.

A small number of clients, with little variation across the Trusts feel that no-one seems to listen to them. These stories describe how clients feel that their voice is not always listened in relation to personal preference, for example the time they wish to get up at or return to bed, as illustrated below:

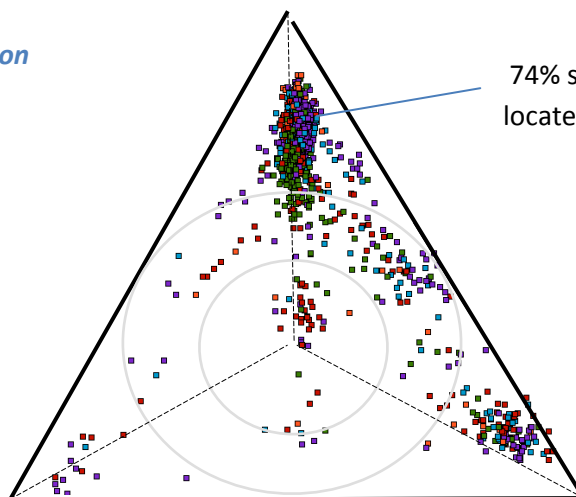
That being said, I sometimes find the care I receive to be a bit impersonal. The attitude appears to be "we know best." I would like to have more say in what my care is like, I am just told how it is going to be.

There is no apparent variation in the responses to this question in the level of involvement in care from the professional groups and support services identified.

Question 6: Is what you are told about your care?

These girls are a credit to the Trust and themselves with not only their professionalism but their friendly and calming nature... have given us a better understanding of his condition which has put us more at ease

Easy to understand and relevant



74% stories located here

That being said, I sometimes find the care I receive to be a bit impersonal. The attitude appears to be "we know best." I would like to have more say in what my care is like.

Mum is 92 and likes to have the same Carers on a regular basis. She does not like new people, especially in the mornings, as she finds it difficult to explain what she requires.

It never makes sense

It depends on who I see

Distribution of % responses across Trusts:

Response	BHSCT	NHSCT	SEHSCT	SHSCT	WHSCT	Overall
Easy to understand and relevant	55%	83%	71%	72%	79%	74%
It never makes sense	2%	0%	2%	1%	0%	1%
It depends on who I see	15%	5%	8%	13%	5%	9%

Discussion

Over 70% of clients, across all the Trusts, feel they what they are told about their care is easy to understand and relevant, the range is from 55% in BHSCT – 83% in NHSCT. Many of these stories highlight how staff take time to explain to clients what is happening in relation to their ongoing care needs with clients reporting that they find the staff are easy to talk to and take the time to listen to their worries and concerns.

In 9% of cases the information received depends on who provides the care with examples of mixed messages, inconsistency in information and clients having to

explain about their treatment when they do not have the same carers. Some stories highlight the lack of communication between the provider organisations as illustrated in the story below:

The only issues I have experienced is that, when dealing with Palliative care, there can be some lack of communication between the different agencies meaning my wife sometimes does not get the required medication on time. This is not acceptable to me given the requirements she has. I can speak out but would be concerned about others who do not feel confident to do so.

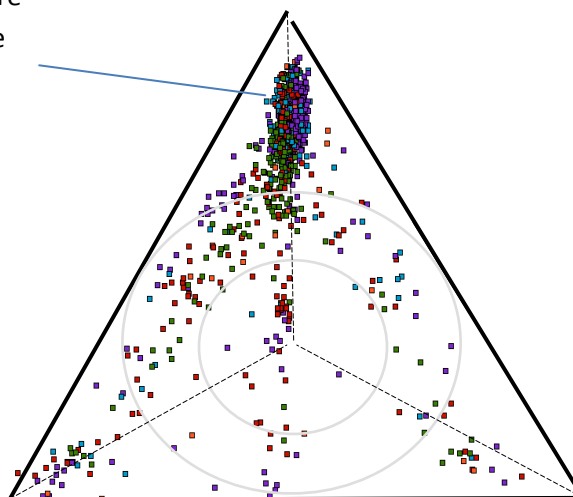
For the small number of clients who cannot make sense of the information they receive, the stories are more indicative of dissatisfaction with the attitude of staff rather than the information they actually receive

Question 7: How are you feeling about receiving your care at home?

Positive and confident

76% stories are located here

Experience - is all now - I have had care for years in my own home and now in my son's home. I love the company and hope as long as I live I will continue to have the help. These young girls are so kind, they chat away just like a ray of sunshine. At first they used to light my fire and make porridge, now I am grateful to be receiving different kind of help.



Some carers do (meet the needs), but most certainly not all of them. Some carers come in and don't even know what they are supposed to do

Just about coping

Very anxious

Distribution of % responses across Trusts:

Response	BHSCT	NHSCT	SEHSCT	SHSCT	WHSCT	Overall
Positive and confident	59%	80%	78%	84%	80%	76%
Just about coping	3%	3%	3%	3%	2%	3%
Very anxious	3%	2%	1%	1%	2%	2%

Discussion

Over 70% of clients feel positive and confident about receiving their care at home with many of these stories describing the professionalism, clinical expertise, care and compassion of the staff who provide the care over a prolonged period of time. There is no apparent variation in the responses aligned to the professional groups or support services who provide they care, however some variation is noted across the Trusts.

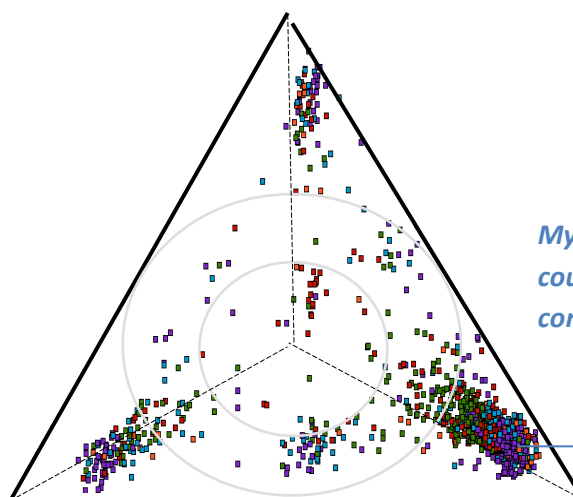
For those who do not feel positive and confident about their care at home, the key messages in the stories are inconsistency in the carers who provide care, care of

patients with dementia, lack of privacy and the time allocation to provide care. In the stories which indicate that the clients or their carers are *just about coping*, the key messages are not enough support and the isolation and loneliness experienced by people who live alone. These stories were most prevalent in the clients who were more than 80 years old.

Question 8: Do your carers ensure your information is kept private?

I feel uncomfortable that others know what is happening

..... was very difficult with confidentially, conversations with visitors to my home that were private was talked about in the community.



My carers are polite, respectful and courteous.. they make me feel comfortable in my own home

67% stories are located here

I don't know what happens to my information

I feel staff are always respectful and aware of my need for privacy

Distribution of % responses across Trusts:

Response	BHSCT	NHSCT	SEHSCT	SHSCT	WHSCT	Overall
I feel uncomfortable that others know what is happening	5%	12%	6%	7%	3%	6%
I don't know what happens to my information	5%	7%	12%	18%	10%	11%
I feel staff are always respectful and aware of my need for privacy	72%	64%	64%	51%	51%	67%

Discussion:

Overall, over two thirds of the clients feel that staff are always respectful and aware of the clients need for privacy, however around 18% of all respondents reported feeling uncomfortable that others know what is happening, that they do not know what is happening with their information, or both. In these stories some clients also describe how they feel they have a lack of privacy in their own home due to the

amount of people who are involved in their care. Clients need to have confidence that at all times their information will be kept private and confidential.

There was some variation in the responses across the Trusts but there did not appear to be any variation in the professional groups/ support services involved.

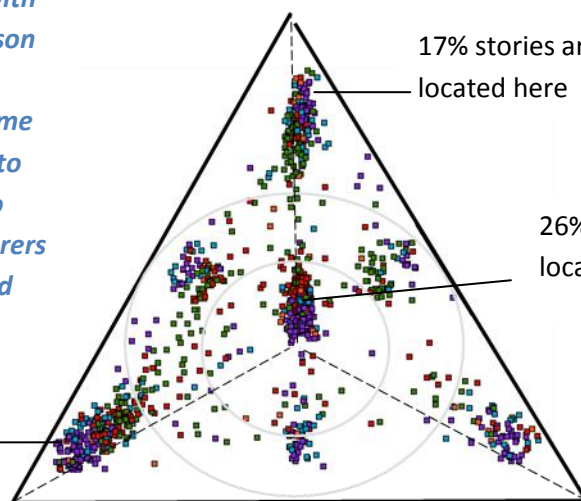
Question 9: What is most important to you in your care?

I grew up on a farm and was very lucky to have married a farmer. We have 40 acres of ground. We used to have cows but now my husband is no longer with usI have three sons and 1 grandson who work on another farm. I really enjoy seeing the girls who care for me I like to have a cup of tea and chat to them sometimes. The day can be so long because my sons work. The Carers make sure I take my medication and that I am safe.

Getting the right treatment and care

I am very happy with the care they provide and I could not manage without them

24% stories are located here



26% stories located here

I have no complaints about my care.. the team have been cheerful, friendly, professional and taken a personal interest in me

Staying at home

Care and compassion of staff

Distribution of % responses across Trusts:

Response	BHSCT	NHSCT	SEHSCT	SHSCT	WHSCT	Overall
Getting the right treatment and care	8%	23%	13%	24%	19%	17%
Staying at home	21%	18%	24%	30%	22%	24%
Care and compassion of staff	3%	5%	10%	9%	4%	7%
Centre of triad (i.e all three responses)	41%	37%	28%	13%	18%	26%

Discussion:

The responses to this signifier are fairly well distributed throughout the triad, with some variation across the Trusts, indicating that it is a combination of factors which are important to people who receive their care at home. While still reported by many as important, care and compassion of staff does not seem to be as important (7%) as getting the right treatment and care, or staying at home. The message of being

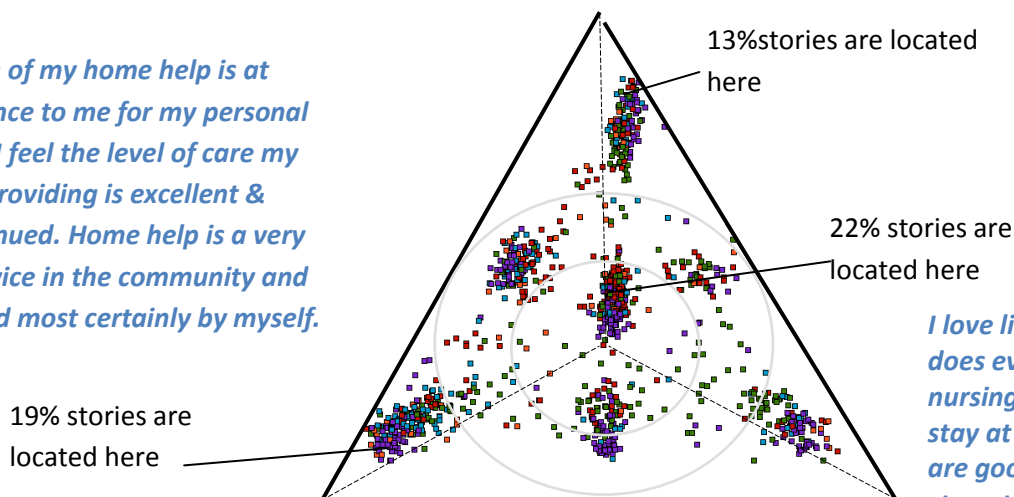
able to stay at home and remain independent is further reinforced in the stories related to this signifier.

People appear to place a high value of receiving *the right care in the right place at the right time*.

Question 10: What enables/supports you to stay at home?

Support from my family and friends

The dedication of my home help is at great importance to me for my personal care & needs. I feel the level of care my home help is providing is excellent & hope it's continued. Home help is a very important service in the community and is highly valued most certainly by myself.



I love living at home. , my son does everything I don't like nursing homes. I would like to stay at home. My care workers are good to me and help me stay at home.

The care package I am receiving

My determination to be in my own home

Distribution of % responses across Trusts:

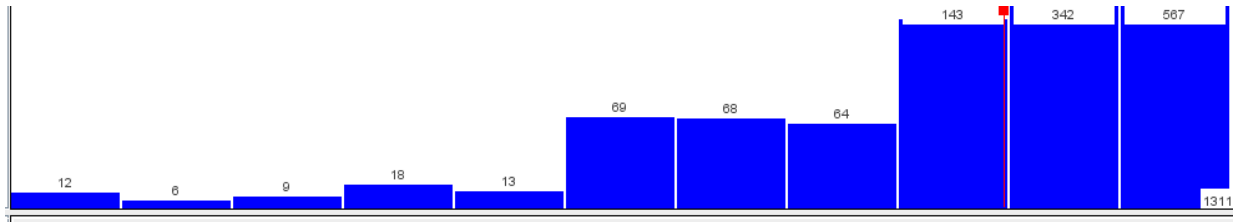
Response	BHSCT	NHSCT	SEHSCT	SHSCT	WHSCT	Overall
Support from my family and friends	12%	16%	10%	15%	20%	13%
The care package I am receiving	10%	17%	21%	33%	14%	18%
My determination to be in my own home	5%	6%	10%	10%	14%	9%
Centre of triad (i.e all three responses)	43%	25%	21%	9%	16%	22%

Discussion

As anticipated the responses in this triad are distributed throughout and are varied across the Trusts, indicating that it is not one single factor which enables clients to remain at home. Their own personal determination is not the main factor - a lot depends on the care package, support from family and friends, or both.

Question 11

Respondents are asked to think about their story, using a scale with two extreme descriptions, and to place a mark on the scale where they feel their story sits in relation to the descriptions, responses are shown below:



Staff just see me as a number

Staff are always so caring and
compassionate

Discussion

It is very evident from the information above, that the majority of clients feel that staff are always caring and compassionate towards them. Most of the stories which are rated as negative seem to be associated with how people perceive they are seen by staff and the attitude of staff towards the client.

5.0 Issues and actions

A high proportion of stories indicate that people who receive care in their own home in all Trusts are very satisfied with the care they receive. This is demonstrated in many of the narratives which describe the compassionate care, help and support which carers deliver. Patients and clients are very grateful for the opportunity to remain in their own home and to have their independence maintained.

Throughout the initiative, patient stories (which are anonymous) have been shared with staff working within these areas. It has provided the staff with an in-depth reflective overview of patient experiences and has enabled them to view from a patient perspective how care has been delivered. This has provided the opportunity for staff to discuss as a team, how to implement improvements and develop local plans. Areas for action to improve the experience of people who receive care in their own homes have been identified through the local Trust findings and are being progressed. Examples of these include the following:

- Findings have been shared with contracts/planning with view to using information in the revision of contracts. Information in relation to the time allocated for calls is being considered for appropriate action
- Progression of a health and wellbeing caring communities model of care to try to address social isolation.
- Many of the stories received support and provide additional evidence of themes identified in user surveys
- Improving communication with people who receive care at home through the roll out of “Hello my name is “campaign
- Local training programmes for staff in relation to the care of clients with dementia
- Ongoing training in Medicines Management with home care workers

However, there are also a number of issues which will require a regional approach in progressing actions to improve their experience of people who receive care in their own homes. These are:

1. Isolation and loneliness: Many stories describe the isolation and loneliness experienced by people who live alone and depend on carers coming into their homes; these stories indicate that these clients are very appreciative of the service which is provided to them. For many of these people their carers are the only people they see on a day to day basis. People who attend day centres appreciate and enjoy the company that they receive and for those who live in sheltered accommodation they enjoy the comfort and security that this type of housing offers.

Action: As it is recognised that social isolation extends to broader areas than health and social care, one of the best mechanisms to address this will be by working collaboratively with individuals, communities and partner organisations through the implementation of Making Life Better (DHSSPS 2013- 2023). The first steps to progress this action will include a workshop with key stakeholders.

2. Timing of calls and time allocation: In the analysis of the stories it is clear that people feel staff are rushing to get everything done in the time allocated, and that although the carers do the best they can, needs are often not met and clients frequently have to rely on family and friends to provide further assistance. The timing of calls are not always suitable to client's lifestyle, for example many patients feel that they return to bed too early in the evening, also timings can be inconsistent at times.

Action: The findings from this phase of 10,000 Voices have been recognised in the review of domiciliary care in Northern Ireland and will be addressed through this review.

3. Care of clients with dementia: Some stories indicate that those providing care do not always have adequate knowledge and skills to care for clients with dementia.

Action: The findings in relation to the knowledge and skills of staff will be addressed through the NI Dementia Learning and Development Framework, which is currently being developed by HSCB and PHA

4. Communication: Some stories highlight that there can be inconsistency in who delivers the care and this often leads to mixed messages in communication with the

client not always knowing who is caring for them. It is therefore vital that all staff introduce themselves and wear name badges. It is also important to clients that their carers know **what matters** to them before leaving their house, for example– drinks, phones at reach, pull back curtains.

Some respondents indicate that they are not always sure what happens to their personal information (11%), with stories highlighting a lack of privacy within their own home.

Actions: The actions in relation to communication, including informing clients what happens to their personal information, will continue to be addressed by Trusts. For those who receive care at home on a long term basis ensure where possible that care is provided by a consistent team of carers who have established a relationship with the client. Extending the **Hello my name is** campaign to community settings has been included as a Patient Client Experience priority regional for 2015/2016.

6.0 Conclusion

As demonstrated in this report it is evident that staff who deliver care in clients' homes contribute significantly to ensuring safe, high quality care and positive experience for patients/clients in Northern Ireland.

10,000 Voices is one of a number of initiatives that the HSCB/PHA and Trusts are implementing to ensure that quality, safety and patient experience is at the heart of all that we do. Key to the success of the 10,000 Voices has been the partnership approach to improving and influencing patient and client experience in Northern Ireland. This enables the people who receive health and social care services to have an opportunity to have their voice heard by the staff who deliver their care and also to have assurance that by sharing their experiences they will be able to contribute to how services are shaped in the future.

7.0 References:

Domiciliary Care Services for Adults in Northern Ireland (2014), DHSSPS (2015)

DHSSPS (2011) Transforming Your Care. A review of health and social care in Northern Ireland

DHSSPS (2012) Quality 2020. A 10 year strategy to protect and improve quality in Health and Social Care in Northern Ireland

DHSSPS Making Life Better, A whole system strategic framework for Public Health 2013 - 2023

Sensemaker® software produced by Cognitive Edge Pte

Response to questions:

1. Are your care needs met in the allocated time?
2. How would you rate the impact of receiving your care at home?

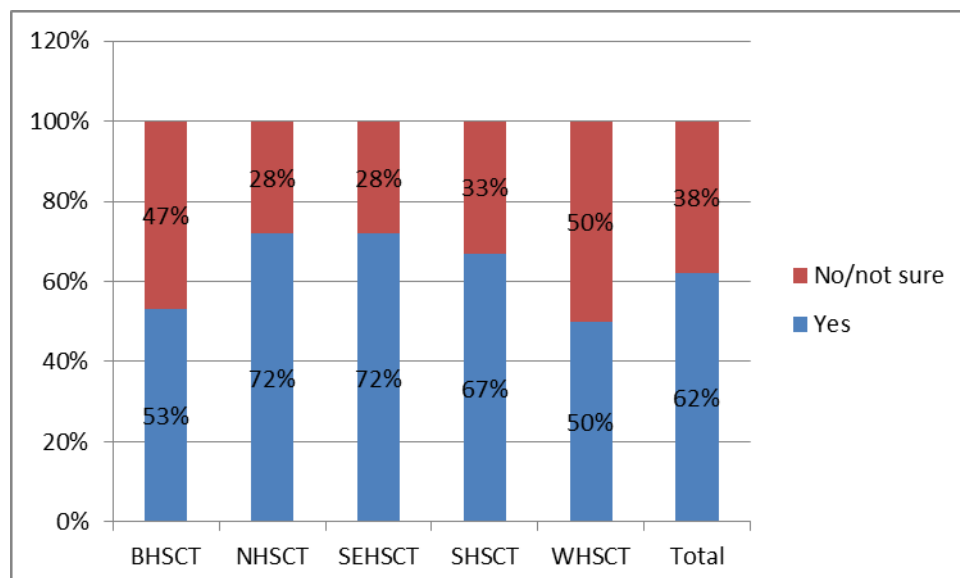
(Breakdown by who provides the care/professional grouping/support services and Trusts)

Area One: Domiciliary Care / Home Help / Home Care Staff / Health Care Assistants

Care delivery to clients who live at home is often provided by several health care professionals and support services who are involved in both the assessment and review of care needs and the actual delivery of care. Participants are asked to identify which health care professionals/ support services are involved in their care, in many cases they identify more than one service. Therefore the numbers are not reflective of the total number of patients but rather the number of patients who have can identify with a particular service.

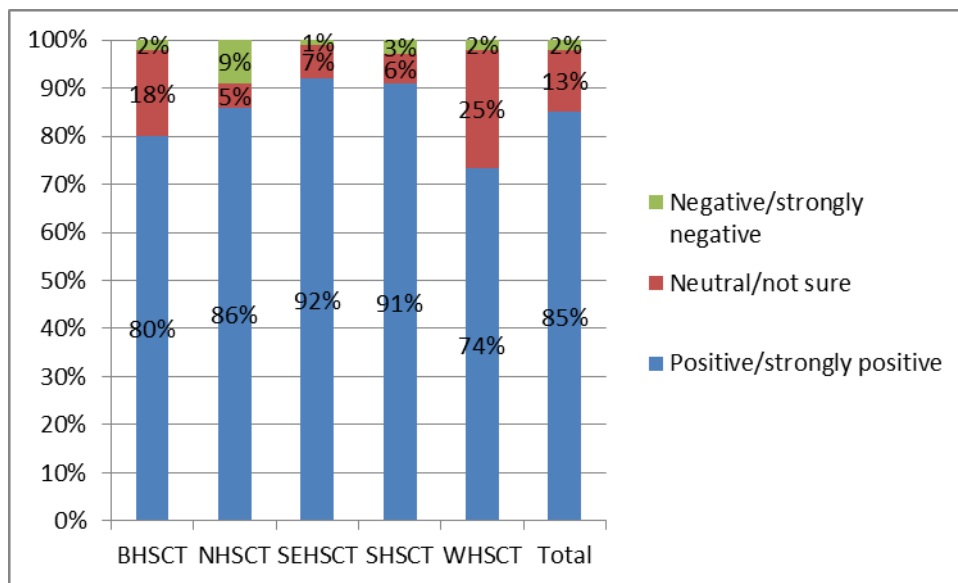
Domiciliary Care / Home Help / Home Care Staff / Health Care Assistants:

Are your care needs met in the allocated time?



Are your care needs met in the allocated time?						
	BHSCT	NHSCT	SEHSCT	SHSCT	WHSCT	Total
Total	265	114	423	156	301	1259
Yes	53%	72%	72%	67%	50%	62%
No/not sure	47%	28%	28%	33%	50%	38%

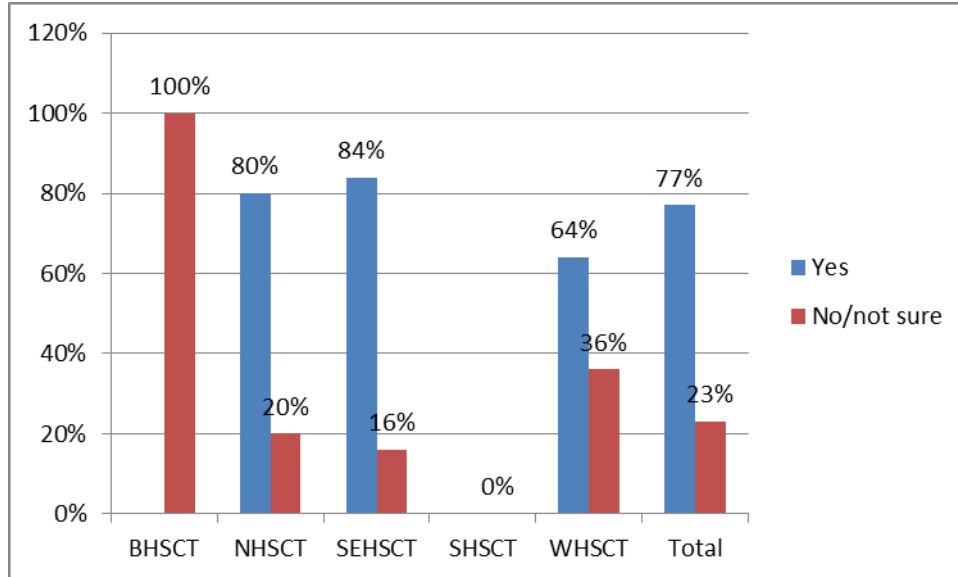
How would you rate the impact of receiving your care at home?



How would you rate the impact of receiving your care at home?						
	BHSCT	NHSCT	SEHSCT	SHSCT	WHSCT	Total
Total	265	114	423	156	301	1259
Positive/strongly positive	80%	86%	92%	91%	74%	85%
Neutral/not sure	18%	5%	7%	6%	25%	13%
Negative/strongly negative	2%	9%	1%	3%	2%	2%

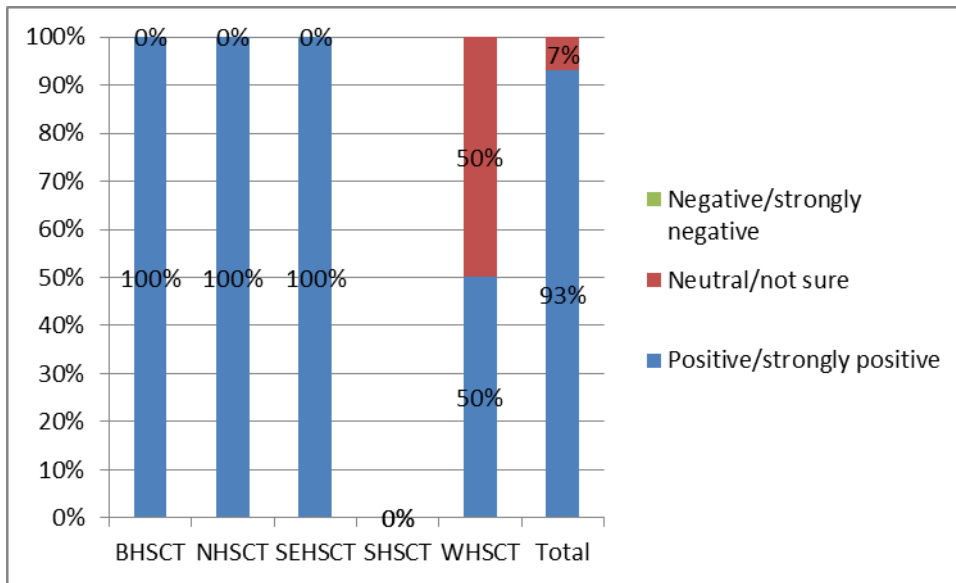
Area 2: Rapid Response / CNRRS / Hospital Diversion Teams

Are your care needs met in the allocated time?



Are your care needs met in the allocated time?						
	BHSCT	NHSCT	SEHSCT	SHSCT	WHSCT	Total
Total	2	11	51	0	11	74
Yes	0%	80%	84%	0%	64%	77%
No/not sure	100%	20%	16%	0%	36%	23%

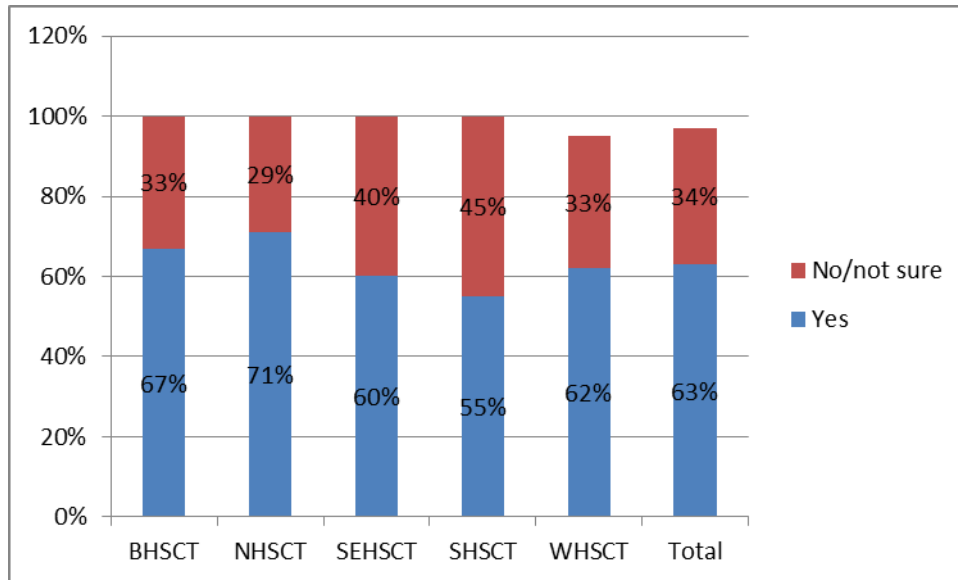
How would you rate the impact of receiving your care at home?



How would you rate the impact of receiving your care at home?						
	BHSCT	NHSCT	SEHSCT	SHSCT	WHSCT	Total
Total	2	11	51	0	10	74
Positive/strongly positive	100%	100%	100%	0%	50%	93%
Neutral/not sure	0%	0%	0%	0%	50%	7%
Negative/strongly negative	0%	0%	0%	0%	0%	0%

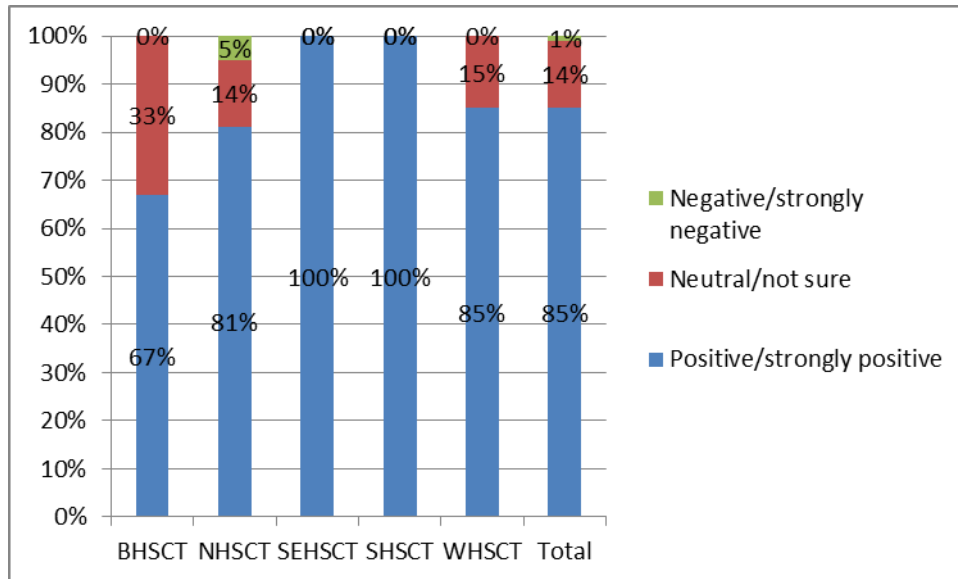
Area 3: District nursing / Specialist Nursing

Are your care needs met in the allocated time?



Are your care needs met in the allocated time?						
	BHSCT	NHSCT	SEHSCT	SHSCT	WHSCT	Total
Total	12	21	10	11	55	109
Yes	67%	71%	60%	55%	62%	63%
No/not sure	33%	29%	40%	45%	33%	34%

How would you rate the impact of receiving your care at home?



How would you rate the impact of receiving your care at home?						
	BHSCT	NHSCT	SEHSCT	SHSCT	WHSCT	Total
Total	12	21	10	11	55	109
Positive/strongly positive	67%	81%	100%	100%	85%	85%
Neutral/not sure	33%	14%	0%	0%	15%	14%
Negative/strongly negative	0%	5%	0%	0%	0%	1%



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